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Patients' preferences for post-treatment breast cancer follow-up in primary care vs. secondary care: a qualitative study

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Abstract

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Objective To explore patients' preferences for follow-up in primary care vs. secondary care.

Methods A cross-sectional design was employed, involving semi-structured interviews with 70 female patients with a history of early-stage breast cancer. Using descriptive content analysis, interview transcripts were analysed independently and thematically by two researchers.

Findings Patients expressed the strongest preference for annual visits (31/68), a schedule with a decreasing frequency over time (27/68), and follow-up > 10 years, including lifelong follow-up (20/64). The majority (56/61) preferred to receive follow-up care from the same care provider over time, for reasons related to a personal doctor–patient relationship and the physician's knowledge of the patient's history. About 75% (43/56) preferred specialist follow-up to other follow-up models. However, primary care-based follow-up would be accepted by 57% (39/68) provided that there is good communication between GPs and specialists, and sufficient knowledge among GPs about follow-up. Perceived benefits of primary care-based follow-up referred to the personal nature of the GP–patient relationship and the easy access to primary care. Perceived barriers included limited oncology knowledge and skills, time available, motivation among GPs to provide follow-up care and patients' confidence with the present specialist follow-up.

Conclusions More than half of the patients were open to primary care-based follow-up. Patients' confidence with this follow-up model may increase by using survivorship care plans to facilitate communication across the primary/secondary interface and with patients. Training GPs to improve their oncology knowledge and skills might also increase patients' confidence.

Introduction

Breast cancer is the most common malignancy and the leading cause of cancer-related death in women worldwide, accounting for 23% of new cancer cases and 14% of cancer deaths in 2008.¹ Survival of breast cancer patients has increased in many countries as a result of early detection through mammography and improved treatment.¹ This will place an increasing burden on follow-up oncology clinics² and primary care, due to the demand for cancer surveillance after completion of primary treatment and general medical care for co-morbid conditions.³ This highlights the need for an effective resource allocation between primary care and hospital care in the future, and possible transfer of follow-up to the general practitioner (GP).³

Transfer of breast cancer follow-up to the primary care setting has to be accepted by all parties involved, including the patients. In two cross-sectional surveys,^{4,5} and a discrete choice experiment⁶ most patients with a history of breast cancer preferred specialist follow-up to GP-led follow-up. In two surveys, primary care-based follow-up was acceptable to 5–39% of the patients^{7,8} and to 55 and 67% of patients invited to participate in two randomized clinical trials comparing hospital and primary care-based breast cancer follow-up.^{9,10} However, these studies used quantitative methods and were performed in a hospital setting.

Qualitative research can provide a deeper understanding of the (non-)acceptance of primary care-based follow-up by patients. To our knowledge, three qualitative studies have explored patients' preferences concerning primary care-based follow-up. One study reported that Australian breast cancer survivors are willing to accept an increased role for their GP in a shared care model,^{11,12} while in another study US breast cancer survivors do not think that their primary care physician has a central role in their survivorship care.¹³ An earlier study found that UK patients prefer access to specialist services, particularly during the early stages of follow-up.¹⁴ As health-care systems may differ between countries worldwide, more

qualitative research concerning patients' preferences in the issue of primary care-based follow-up is needed. We conducted a qualitative study among Dutch patients recruited in general practice, in which the aim was to describe patients' preferences for follow-up in primary care vs. secondary care.

Methods

Design and setting

A qualitative study was performed in the context of the Dutch healthcare system, in which primary care has played a central role for many years. Almost all citizens are registered with a GP, who deals with 95% of health problems presented by patients.¹⁵ At the time this study was conducted, the Dutch breast cancer guidelines recommended hospital follow-up for 5 years, including yearly mammography. Physical examination had to be performed every 3 months in the first year, every 6 months in the second year and annually thereafter. After 5 years, yearly follow-up visits and mammography appointments in the hospital were recommended for patients aged ≤ 60 years. Patients aged > 60 years who had undergone mastectomy had to be referred to the national screening programme for two-yearly mammography. For patients aged > 60 years, and treated with breast-conserving therapy, discharge to their GP for yearly physical examination was recommended, combined with two-yearly mammographic follow-up in the hospital.^{16,17}

A cross-sectional design was employed, involving semi-structured interviews with 70 female patients with a history of early-stage breast cancer recruited from GP offices of the Registration Network Groningen (RNG). This general practice research network was established in 1989 and consists of three group practices with 17 GPs and a dynamic population of about 30 000 patients in the city of Groningen and the smaller towns Hoozevee and Sappemeer in the northern part of the Netherlands.¹⁸ To protect patient identity, ref-

erence numbers were assigned, and data were stored against these numbers. According to the Institutional Review Board of the University Medical Center Groningen (UMCG), no approval was needed as this non-invasive study was not subject to the Dutch Medical Research Involving Human Subjects Act. The principal aim of this Act is to provide protection for human subjects who take part in medical research.^{19,20}

Recruitment of patients

Using the RNG database, we searched for patients who had a recorded code for female breast malignancy in their record between 1998 and 2007 and who were also registered with a participating GP at the start of the study (1 January 2009). We identified 167 of such patients (Fig. 1). Confirmation of breast cancer in history was obtained by going back to the participating general practices; subsequently, additional information about breast cancer diagnosis, stages, treatments and recurrences was collected for these women.¹⁸ GPs from the

RNG were asked to include patients with a history of breast cancer who were able to participate in the study. A total of 18 patients were excluded from the study for the reasons shown in Fig. 1. Patients with distant metastasis at diagnosis or during follow-up were excluded because they are expected to use more (palliative) health care in general practice than patients treated with curative intent. Eligible patients ($n = 149$) were sent a letter, an information leaflet about the study and an informed consent form by their own GP, to ensure that only patients who gave their written informed consent ($n = 72$) were contacted and interviewed by the researchers. Two patients were excluded after interviewing because of distant metastasis during follow-up, or missing data.

Interview guide development and data collection

Based on a literature review and interviews with three patients not linked to the RNG, a semi-structured interview guide was developed. The introductory part of this guide addressed

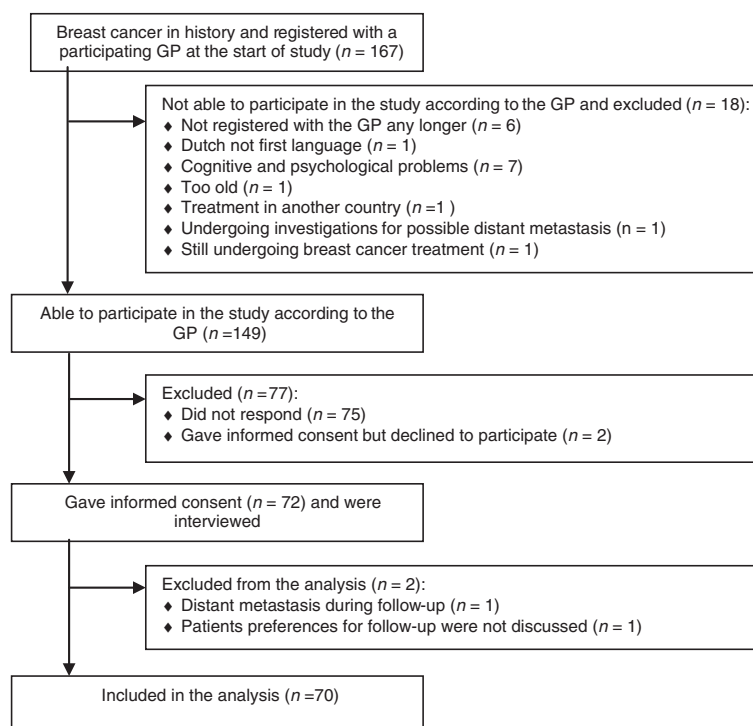


Figure 1 Flow diagram of the identification and inclusion of patients with early-stage breast cancer.

patients' experiences with diagnosis, treatment and follow-up to let patients 'tell their story' of the breast cancer experience. The first part focused on patients' preferences for follow-up in primary care vs. secondary care; The second part focused on patients' perceptions of the aims of follow-up (Appendix S1). In this article, we report on patients' preferences for follow-up. To test the interview guide, pilot interviews were conducted with 10 patients from the RNG. Themes related to care provider continuity emerged from these interviews and were added to the interview guide. The final interview guide was used in the remaining 62 interviews.

Most interviews were conducted by a final year medical student (CS, male), who had completed his clinical training and participated in the research project to finish his Master's degree. He had passed the tests related to learning communication skills and clinical interviewing, as these are part of the medical school curriculum. One patient requested to be interviewed by a female researcher (CR). Patients were interviewed individually in their own home ($n = 69$), in the general practice ($n = 2$) or at our Department of General Practice ($n = 1$). Each interview lasted 30–60 min, was audio-recorded and transcribed *verbatim*. Confidentiality of the interview data was discussed at the beginning of the interviews. Patients were assured that their data would be processed and analysed anonymously.

No relationship was established between the researchers and the patients prior to study commencement. Before being contacted, the patient did not know anything about the researchers, except for a name, occupation and the reason for conducting the interview. This information was provided in the letter, the information leaflet and the informed consent form. Furthermore, the researchers briefly introduced themselves at the beginning of the interview.

Data analysis

Descriptive statistics were used to describe patients' characteristics. Interview data were

coded by two researchers using descriptive content analysis.²¹ First, one researcher (MdF, female) organized transcribed text concerning patients' preferences for follow-up into display tables, as described by Miles and Huberman.²² Next, two researchers independently reviewed these tables and coded patients' responses based upon the predetermined themes in the interview guide (Table 1). The researchers discussed any discrepancies in the findings until consensus was reached. Summaries were written and illustrated with quotes of patients. For the predetermined themes, the numbers of responses were counted. In this way, a cross-case approach with a variable-oriented strategy was used in the data analysis.^{22,23} Data saturation was not determined as data analysis took place after completion of data collection. However, after analysing the majority of the interviews, no new themes appeared indicating saturation.

Results

Characteristics of the included patients are presented in Table 2. Median age at the time of the interview was 62.6 (range 34.5–88.4) years. Median time since breast cancer diagnosis was 7.0 (range 1.0–23.1) years. No significant differences were found between the characteristics of the included patients ($n = 70$) and the non-respondents/excluded patients ($n = 79$) (data not shown).

Table 1 Patients' preferences for follow-up: predetermined themes

	Discussed, <i>n</i> (%)
Follow-up frequency	68 (97.1)
Follow-up duration	64 (91.4)
Care provider continuity*	61 (87.1)
Care provider: first choice	56 (80.0)
GP-led follow-up	68 (97.1)
Care provider continuity: GP vs. specialists*	38 (54.3)

*These themes emerged from the pilot-interviews ($n = 10$) and were added to the interview guide after these interviews.

Table 2 Characteristics of the patients included in the analysis

	<i>n</i> = 70
Age at diagnosis, median (range), years	55.2 (27.4–83.9)
Breast cancer	
T stage, <i>n</i> (%)	
Tis/T1	43 (64.2)
T2/T3/T4	24 (35.8)
Unknown	3
Breast cancer	
N stage, <i>n</i> (%)	
N0	48 (68.6)
N+	22 (31.4)
Unknown	
Surgery, <i>n</i> (%)	
Lumpectomy*	40 (57.1)
Mastectomy†	30 (42.9)
Systemic treatment, <i>n</i> (%)	
None	12 (17.1)
Chemotherapy	35 (50.0)
Endocrine therapy	16 (22.9)
Chemotherapy + endocrine therapy	7 (10.0)
Recurrent breast cancer during follow-up, <i>n</i> (%)	
Locoregional	3 (4.3)
Contralateral	2 (2.9)
Age at time of interview, median (range), years	62.6 (34.5–88.4)
Time since diagnosis, median (range), years	7.0 (1.0–23.1)

*Including patients treated with lumpectomy, with and without radiation therapy.

†Including patients treated with lumpectomy followed by mastectomy, with and without radiation therapy.

Follow-up frequency

Patients expressed the strongest preference for annual visits (31/68) (Table 3). Other frequently mentioned options included visits twice a year (10/68) and a schedule with a decreasing frequency over time (10/68). During the interviews, 27 patients said they would (also) like a schedule with a decreasing frequency over time.

Annual visits

For all that fuss I think once a year is certainly enough; I don't need to have that mammogram more often. (P21, age 65 years)

Table 3 Patients' preferences for follow-up: frequency and duration

	<i>n</i> (%)
Frequency (<i>n</i> = 68)	
< Every year	2 (2.9)
Every year	31 (45.6)
Twice a year	10 (14.7)
> Twice a year	6 (8.8)
Not more/less often than at present	6 (8.8)
Decreasing frequency over time*	10 (14.7)
Other	3 (4.4)
Duration (<i>n</i> = 64)	
< 5 years	1 (1.6)
5 years	8 (12.5)
7 years	2 (3.1)
10 years	16 (23.5)
> 10 years	20 (31.3)
Lifelong	11 (17.2)
At least 5 years	3 (4.7)
Longer than at present	2 (3.1)
Duration recommended by the specialist	2 (3.1)
No preference	2 (3.1)
Other	8 (12.5)

*Of all patients (*n* = 68), 27 would (also) like a schedule with a decreasing frequency over time.

A schedule with a decreasing frequency over time

Well, 3 months and then half a year, that scaling down, I like that. And then after 2 years, once every year. Yes, I think that's good. (P06, age 86 years)

Follow-up duration

The most preferred duration of follow-up was > 10 years, including lifelong follow-up (20/64) (Table 3). Other frequently mentioned options were 10 years of follow-up (16/64) and 5 years of follow-up (8/64).

Over 10 years, including lifelong follow-up

The way I think about it now: maybe forever. Only it was 5 years ago... and after 10 years I might say, of course not. But that feeling, it does gives you a bit of security, if you're checked at

least once a year ... So, as far as I'm concerned I'd go for the expensive solution - let them go on controlling me for a long time... (P33, age 57 years)

Care provider continuity

The majority of patients (56/61) preferred to receive follow-up care from the same care provider at each visit. Most explanations for this preference are related to a personal doctor–patient relationship (of trust) and the physicians' knowledge of the patients' history (so that patients do not have to present their story over and over again). Three patients considered a lack of care continuity as an advantage in terms of receiving different opinions. Two others declared that they were neutral with respect to care provider continuity.

A personal doctor–patient relationship

Great. You build up a sort of band. If it would be someone else every time, then I'd think: what have I got now. They do have something on paper, but still ... I wouldn't like to keep having a different GP. (P39, age 72 years)

Knowledge of the patients' history

Then Doctor X was sick, and then another doctor came who said: 4 years tamoxifen? Not 5 years? And then I had to explain that... and then another doctor came and then something else was unclear ... but because it was someone else every time, I found that very unpleasant. (P67, age 34 years)

Follow-up care provider: first choice

During the interviews, patients were asked which care provider should provide their follow-up. About 75% (43/56) preferred specialist follow-up to other follow-up models, including GP-led follow-up (4/56), nurse-led follow-up (2/56) and follow-up alternately provided by specialist and/or GP and/or nurse (5/56). Two patients preferred to receive follow-up care from someone who can best provide this care.

Specialist follow-up

Well, you could say the GP because he knows you the best. But yes, the surgeon really knows more about it So yes, then rather the surgeon. (P30, age 48 years)

GP-led follow-up

Follow-up provided by the GP would be accepted by 57% of patients (39/68) (Table 4). One of these patients found this follow-up

Table 4 Patients' preferences for follow-up provided by the general practitioner (GP) (*n* = 68)

	<i>n</i> (%)
Acceptance	
There is a GP-patient relationship of trust	39 (57.4)
Patient receives more personal attention in general practice than in the hospital	
General practice is nearby	
General practice is easily accessible	
Provided that there is good communication between the GP and specialists	
Provided that the GP has sufficient knowledge about follow-up	
No acceptance	
GP has a broad medical knowledge	28 (41.2)
GP is not specialised/educated in follow-up	
GP has insufficient experience/ knowledge regarding follow-up	
GP has too little time available/ high workload for providing follow-up	
GP is not motivated to provide follow-up	
Patient has less confidence in GP/ more confidence in specialists	
Patient feels confident/is satisfied with present hospital follow-up	
GP missed breast cancer diagnosis	
GP has to refer patients to the hospital	
GP was not involved during the active treatment phase	
Mammography has to be performed in the hospital	
There are effective links within the hospital	
Neutral	1 (1.5)

model acceptable after 5 years of hospital follow-up. Another commented that she would only accept follow-up provided by her own GP (and not by other GPs). None of the characteristics presented in Table 2 were significantly associated with patients' willingness to accept GP-led follow-up (data not shown). Patients' motives for accepting this follow-up model included having a relationship of trust with the GP, receiving more personal attention in general practice than in the hospital, and having less travelling/waiting time as the general practice is nearby and easily accessible. However, good communication between GPs and specialists and sufficient knowledge among GPs about follow-up, were considered essential by the patients.

Less travelling time

Well, I'd approve of that ... As you get older, that's much better for us. Because it's close by and then you don't have to go to the hospital and you don't have that dreadful waiting room. (P58, age 70 years)

Good communication/sufficient knowledge

I find that OK, as long as he discusses everything with the various doctors and he stays up to date. Because in general the GP is a bit less up to date about what's really going on in terms of therapies. (P10, age 36 years)

Follow-up provided by the GP would not be accepted by 41% (28/68) (Table 4). One patient felt neutral with respect to GP led follow-up. Patients who found GP-led follow-up unacceptable were concerned about (limited) oncology education, knowledge and experience among GPs (Table 4). Furthermore, they thought that GPs had too little time available and were not motivated to provide follow-up care. Patients expressed less confidence in their GP and more confidence in specialists with respect to breast cancer follow-up. Also, patients were satisfied with the present hospital follow-up. Other barriers to GP-led follow-up included GPs missing breast cancer diagnosis, GPs seen as referring agents to the hospital, no GP involvement during the active treatment phase, mammography

appointments in the hospital and perceived effective links within the hospital.

GPs' limited experience

I think - the more experienced your fingers are, the faster you can detect something ... And a GP has just seen someone with a runny nose, and then I come in between with my breasts, because there's also a man with a sore toe waiting. According to my feeling, it seems better to have someone do this - who's doing this every single day. (P44, age 61 years)

Care provider continuity: GP vs. specialists

When patients could choose between follow-up provided by their own GP vs. follow-up provided by different specialists (lack of care provider continuity), 55% of these patients (21/38) would choose the first option, while 34% (13/38) preferred the second option. In that case, two patients would terminate follow-up. One patient would go to another hospital for follow-up, while another patient stated she had no preference for either of the options.

GP-led follow-up

Yes, then rather with the GP - that's the contact that you still have. And also ... the feeling that there's attention for you at that moment, instead of being just a number on a letter, and someone just gives you the message (P62, age 55 years)

Discussion

This qualitative study explored preferences for breast cancer follow-up in primary care vs. secondary care, among female patients with a history of early-stage breast cancer recruited in general practice. The women expressed the strongest preference for annual visits, a schedule with a decreasing frequency over time, and follow-up > 10 years, including lifelong follow-up. The majority preferred to receive follow-up care from the same care provider over time, for reasons related to a personal doctor-patient relationship and the physicians' knowledge of

the patients' history. About 75% preferred specialist follow-up to other follow-up models. However, follow-up by the GP would be accepted by 57%, provided that there is good communication between GPs and specialists and sufficient knowledge among GPs about follow-up. Perceived benefits of GP-led follow-up referred to the personal nature of the GP–patient relationship and the easy access to primary care. Perceived barriers to GP-led follow-up included limited oncology knowledge and skills, time available, motivation among GPs to provide follow-up care and patients' confidence with the present specialist follow-up.

In line with our results, others have also shown that patients with a history of breast cancer and participating in a hospital follow-up programme strongly prefer visits once or twice a year (depending on time since treatment) and lifelong follow-up.^{4,8} Before entering hospital follow-up, most patients expect to go back to the clinic once or twice a year, but are uncertain as to how long they would remain in follow-up.²⁴ As in our study, others also reported the importance of care provider continuity.^{7,11,12,14,25,26} Among Australian breast cancer survivors, the main reason for preferring to receive follow-up care from the same care provider over time was the doctor–patient relationship developed during the active treatment phase.¹²

Our study supports earlier quantitative^{4–6} and qualitative^{11–13} findings that patients with a history of breast cancer prefer specialist follow-up to primary care-based follow-up. When interpreting these findings, it should be kept in mind that patients tend to prefer the most familiar situation.^{4,6} In our study, all patients were diagnosed with breast cancer before 2008; at that time, Dutch GPs did not play a formal role in breast cancer follow-up care. Other studies reported that patients who already received breast cancer follow-up or survivorship care from their primary care physician were satisfied with it^{27–29} and did not report any disadvantage.¹¹ Furthermore, patients' preference for specialist follow-up seems to be related to a strong specialist–patient relationship developed

during the active treatment phase.^{11,12} If follow-up is transferred to the primary care setting, formal involvement of GPs during the active treatment phase might increase patient's confidence with primary care-based follow-up.

In the present study, despite patients' preference for specialist follow-up, primary care-based follow-up was acceptable to 57% of patients, compared to 5–39% of patients in two surveys^{7,8} and 55 and 67% of patients participating in two randomized clinical trials.^{9,10} Patients in our study, similar to patients in an Australian qualitative study,^{11,12} considered the GP–patient relationship and the easy access to primary care as benefits of primary care-based follow-up. However, good communication between GPs and specialists and sufficient knowledge among GPs about follow-up were regarded as prerequisites to accept this follow-up model. Breast cancer survivors in other countries found deficiencies in the communication between primary care and specialist care^{12,28} and felt that written documentation or on-going communication between their specialists and primary care physicians would be helpful in coordinating their care.¹³ Therefore, survivorship care plans may be useful instruments to facilitate communication among patients and health-care providers.^{30–32}

Limited education, knowledge, experience, time and motivation among GPs were perceived barriers for the patients both in our study and in three previous qualitative studies^{11–14} to accept primary care-based follow-up. Furthermore, in another qualitative study, the majority of women receiving hospital follow-up care ($n = 15$) did not contact their GP because they considered them to be too busy or to be lacking in specialist knowledge.²⁶ Informing women of the educational activities of their GP might increase their confidence with primary care-based follow-up.¹¹

Major strengths of this study are the large sample of participants ($n = 70$) recruited in a community setting (general practice) and that the sample covers the preferences for follow-up of women (aged 34–88 years) with a history of

breast cancer and living from 1 to 23 years after diagnosis. Trustworthiness of the findings was enhanced by the use of *verbatim* transcripts and by using two researchers to code patients' responses based upon the predetermined themes in the interview guide. Member checking (whereby participants provide feedback on the preliminary analysis) was not performed as we considered this to be too time-consuming for the patients. The main limitation of this study concerns incomplete data collection in the way that not all predetermined themes in the interview guide were discussed with all patients. As the flow of the dialogue was mainly set by the patients, the (main) interviewer did not strictly follow the interview guide over time, probably due to limited interviewing experience. The fact that predetermined themes in the interview guide were not discussed with all patients was discovered during data analysis as the interviews were analysed at the end, rather than in an iterative process. As gender mediates the production and analysis of qualitative data,³³ another limitation might be that female breast cancer patients in the present study were interviewed by a male interviewer. However, only one patient specifically requested to be interviewed by a female researcher. Furthermore, transcribed text showed that patients spoke freely about their preferences for follow-up. Therefore, we do not believe that using a male interviewer seriously affected patients' responses concerning their preferences for follow-up.

In summary, over 50% of patients were open to the possibility of primary care-based follow-up. Patients' confidence with this follow-up model may increase by using survivorship care plans to facilitate communication across the primary/secondary interface and with patients. Training GPs to improve their oncology knowledge/skills might also serve to improve patients' confidence.

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Conflict of Interest

No conflict of interests have been declared.

Supporting Information

Additional Supporting Information may be found in the online version of this article:

Appendix S1. Main part of the semi-structured interview guide.

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